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Influence of Emotional Caregiving in Presence of Social Support as a Mediating Variable on Caregivers' Stress of Cancer Children in Pakistan

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Abstract:
Increasing rate of pediatric cancer has shifted the patients from hospitals to the home settings. This shift involves the informal caregivers of pediatric cancer to face several social and emotional challenges that may result in caregiving-related stress. Stress process theory suggests a mediating variable such as social support in managing the caregivers' stress. This study examines the stress of caregivers of cancer children in terms of emotional caregiving and social support using Berlin Social Support Scale, Medical Outcomes Study- Social Support Survey and Modified Caregiving Strain Index. This cross-sectional study involved 120 caregivers of children with cancer aged 0-19 years from cancer hospitals of Punjab, Pakistan. Multivariate analysis was conducted in addition to descriptive statistics. Results showed that emotional caregiving to the patients and caregivers' stress were positively correlated and social support acts as a mediator in coping with the caregivers' stress. The findings of this study exhibit the significance of involving multiple social resources while studying the process of cancer caregiving by illustrating the distinguishing effect of social support on caregivers' stress of cancer patients.

Keywords: *Cancer children, caregiving, social support, caregivers' stress*

1. Introduction

Globally, the burden of cancer is predicted to rise to 21.7 million new cancer cases and 13 million cancer deaths by 2030. In Asian countries, cancer has become the leading cause of death with around four million new cases and two million deaths (International Agency for Research on Cancer [IARC], 2014). However, the estimated burden of cancer in future will be larger due to varied lifestyles that increase risk of cancer in economically developing countries (Bray, Jemal, Grey, Ferlay, & Forman, 2012). Pakistan as a developing country is not an exception to the expanding circle of cancer. In the last two decades, Pakistan has observed a substantial growth in number of cancer cases claiming not less than 100,000 lives in 2015 (The News, 2016). The reliable figure of cancer is missing but it is estimated that new cases of cancer during upcoming years will vary between 1.4 to 1.67 million including the children and adolescents (Rubab, Ibtisam, Samina, Azeemi, & Naveed, 2015).

Although advancements in treatments and medicines has increased the life expectancy but the number of deaths due to cancer is increasing every year. These continuing alterations in the health care system leads to the shift of cancer patients to the home setting from the hospitals (National Family Caregivers Association, 2010). This transference directs the involvement of family members in caring of cancer patients which may reflect an increasing effect of cancer on these informal caregivers (Meecharon, Northouse, Sirapo-ngam, & Monkong, 2013). Panganiban-Corales and Medina (2011) have found that caregivers of cancer children and adolescents are less stable and face more stress as compared to the caregivers of other diseases.

It has been found in literature that childhood cancer leads to the various disturbances in the life of a caregiver resulting in several stressors of different impacts and durations (Klassen, Raina, McIntosh, Sung, Klaassen, O'Donnell, Yanofsky, & Dix, 2011). The effects of childhood cancer on the informal caregivers are often due to the fact that they are considered to be deeply involved in their caring process by providing extraordinary, uncompensated such as physical care and emotional care (Ennis, Rosenbloom, Canzian, & Topolovec-Vranic, 2013; Viana, Gruber, Shahly, Alhamzawi, Alonson, Andrade, & Kessler, 2013). Besides, physical care, emotional care including feelings of empathy, comfort and encouragement provided to the cancer children and adolescents creates additional fears and challenges to a caregiver (Esper, 2010; Marcusen, 2010). In addition, because children are not competent enough to make their own decisions therefore, this responsibility also lies on the caregivers leading to the significant psychosocial stress on caregivers. Stress, in this scenario, is the burden felt by the caregiver because of physical, emotional and financial stress as a consequence of

his/her caregiving roles (Stenberg, Ruland, & Miaskowski, 2010). Thus, this study aims to scrutinize the influence of emotional caregiving on stress of caregivers as well as to examine the mediating effect of social support on caregivers' stress.

Beck and Lopes (2007), in their study among caregivers of cancer children found that 78% of the caregivers had caregiver role strain and 100% presented risk for caregiver role strain. It is because becoming a caregiver is often regarded as a social and ethical obligation and fulfillment of these obligations can be satisfying or discouraging (Ferrell, Grant, Otis-Green, Juarez, Hurria, & Bhatia, 2011). Therefore, to perform caregivers' role appropriately, in addition to physical caregiving, a caregiver has to be emotionally involved with the patient by providing him feelings of worth and value which increases the caregiving burden eventually leading to the caregiver's stress. Caregivers of cancer children and adolescents providing higher levels of emotional support are found to report more negative outcomes and are less likely to effectively care for a patient as well as themselves (Panganiban-Corales et al., 2011).

Bartolo, Luca, Serrao, Sinforiani, Zucchella and Sandrini (2010) states that caregivers are the second victims of the disease who have to become caregiver with minimal preparation, therefore, they are at risk of developing mental health problems due to the demands of the caregiving role if they appraise their caregiving situation as stressful. Literature (Casale, & Wild, 2012; Clay, Grant, Wadley, Perkins, Haley, & Roth, 2013; Rafiyah, Suttharangsee, & Sangchan, 2011) shows that the caregivers' ability to survive well in stressful situations depends on the social resources. Family caregivers need help from other people to maintain their own well-being and role as family caregivers. Different caregiving theoretical frameworks from literature examining the contribution of social support to caregivers' stress proposes that the objective aspects of caregiving do not directly influence the mental health of caregiver but are mediated by a subjective evaluation of their situation. In addition, Pearlin's stress process model (1990) proposes that this mediating variable is the degree to which a patient's illness hinders the caregiver to participate in a variety of valued activities.

It is believed that social support from meaningful others provides a sense of belonging by enhancing the feelings of being valued and the self-esteem that helps in resolving different problems (Marsland, Long, Howe, Thompson, Tersak, & Ewing, 2013). It can be of particular significance during caregiving as it is observed to sustain and improve mental health whereas, disruption in social support results in stress, or, in other words, social support largely impact the psychological adjustment of the caregivers of children suffering from cancer rather than disease-related factors (Dale, Mohile, Eldatah, Trimble, Schilsky, Cohen, Muss, Schmader, Ferrell, Extermann, Nayfield, & Hurria, 2012).

To date, numerous studies (Penning, & Zheng, 2016; Soylu, Ozaslan, Karaca, & Ozkan, 2015; Masood, Beenish, Zubia, & Shaukat, 2012) have discussed the effects of caregiving on caregiver's mental health. Generally, caregiving has been empirically suggested to be stressful thus, negatively influencing the health of caregivers. However, inadequate research in Pakistan has been conducted on the implications of particularly emotional caregiving and its outcomes as well as the role of social support in influencing these implications. Moreover, there are cultural differences that exist between caregivers from the European and Western cultures because caregivers in Pakistan are mostly influenced by cultural expectations based on the extended family system, therefore, studies conducted in West may not be applicable in Pakistan. Furthermore, people in Pakistan are living an average life where they can meet both ends without an ease, this causes a financial strain and as a result the caregiving situation becomes more stressful compared with caregivers from other well-resourced countries (Nazish, Riaz, Haider, Lubna, Amna, & Ahsan, 2010).

Therefore, the preceding review recommends to concentrate on the effects of emotional caregiving to the patient and social support to the caregiver in order to better understand the phenomenon of caregiving. To date, none of the studies to date in Pakistan has examined the influences of this constellation of variables: emotional caregiving, social support and caregivers' stress. The current study discusses these gaps in literature by examining the stress and emotional caregiving to the cancer children and adolescents, as well as effects of presence of social support to the caregivers during emotional caregiving. The underlying assumption was that the higher level of emotional caregiving would be associated with higher level of caregivers' stress and mediating effect of social support would be associated with low level of caregivers' stress.

Hence, in accordance with the general stress process theory (Pearlin et al., 1990). Hypothesis 1 states that higher levels of emotional caregiving to the patient would be associated with higher stress of caregivers, because emotional caregiving is associated with higher self-worth and thus along with other caregiving roles, providing emotional caregiving leads to higher level of stress (Cousino & Hazen, 2013). Hypothesis 2 states that social support to the caregivers while providing emotional caregiving may lower caregivers' stress acting as a mediating variable as availability of social support represents that one is accepted by others, thus helping in reducing stress (Kong, Zhao, & You, 2013; Wang, Cai, Qian, & Peng, 2014).

2. Method

2.1. Participants

One hundred and twenty primary caregivers of children with cancer aged 0-19 years were taken as a sample from the four cancer hospitals of Punjab, Pakistan. Cluster sampling was done to select the hospitals while participants were selected with simple random technique.

2.2. Instruments

Berlin Social Support Scale (BSSS) by Schwarzer and Schulz (2013) was used to examine the emotional caregiving to the cancer children. This twelve-item scale has questions related to emotional caregiving to the patient. The scale used for this instrument is 5-point Likert scale ranged from (1) strongly disagree to (5) strongly agree with 3 negative items. High score on the scale indicates the extent of providing emotional caregiving. The Cronbach's Alpha value of this scale is 0.75.

Medical Outcomes Study: Social Support Survey (MOS-SSS) by Sherbourne and Stewart (1991) was used to analyze the social support. This instrument comprises of questions regarding social support provided to the caregiver in stressful circumstances. The ten items of the instrument are measured on 5-point Likert scale ranging from (1) strongly disagree to (5) strongly agree. The high score indicates that the respondent receives maximum social support. The reliability of instrument was found to be 0.97.
Modified Caregiving Strain Index (MCSI) by Thornton and Travis (2003) was used to assess the caregivers' strain as a result of providing care to the close ones. Ten items of this instrument are measured on 3-point Likert scale ranging from (1) on a regular basis to (3) never. The high score indicates the higher level of caregivers' stress. Value of Cronbach's Alpha was 0.90 for this scale.

2.3. Data Collection
This study is descriptive and cross sectional in nature and is conducted in five cancer treatment hospitals of Punjab, Pakistan. Primarily, Medical Superintendents of each selected hospitals were consulted to get permission for collection of data. Later, primary caregivers willing to participate in the study were consulted and informed consent form was signed followed by the completion of the instruments selected for this study.

2.4. Data Analysis
Data gathered was keyed in to the Statistical Package for the Social Sciences (SPSS v23) software where descriptive statistics described the demographics of the respondents. Next, the SmartPLS v3.0 was used to determine the outer model and the inner model by assessing reliability and validity of the scales and testing of hypotheses.

3. Results
The questionnaires were distributed to 120 respondents where the response rate of questionnaires was 100%. The results of common method bias showed that each factor is explaining 12.4% of variance. Only one missing value was found and values of skewness and kurtosis for the normality of data were found to be within acceptable range of <2 to <7 respectively. Among the sample, 81% of the respondents were females and 19% were males. Additionally, 90% were parents of the cancer children where only 10% were siblings. Most of the respondents (73%) were in between 41-50 years of age while 14% were in between 31-40 years and the rest 13% lies in range between 20-30 years of age. About 83% of the caregivers were married while 17% were single or divorcee. The highest education level of caregivers was a university degree (48%) while others were having varied levels such as primary (9%), secondary (19%) and intermediate (24%). 48% of caregivers were having government job while the rest 22% were private job holders and 30% were running their own business. The duration of illness of children mostly lies within 0-3 years (69%) where 31% were cancer patients from more than 3 years.
For multivariate analysis, SmartPLS was used where all variables were taken as reflective and were treated as first order constructs. Initially, the analysis of measurement model (outer model) was conducted that ensured the reliability and validity of the constructs as shown in Table 1.

Variables	Items	Loadings	Cronbach's Alpha	CR	AVE	Discriminant Validity
CS	CS1	0.854	0.938	0.948	0.645	0.803
	CS10	0.789				
	CS2	0.862				
	CS3	0.853				
	CS4	0.61				
	CS5	0.8				
	CS6	0.79				
	CS7	0.821				
	CS8	0.813				
	CS9	0.812				
EC	EC1	0.74	0.912	0.926	0.534	0.731
	EC10	0.759				
	EC11	0.772				
	EC2	0.812				
	EC3	0.793				
	EC4	0.708				
	EC5	0.62				
	EC6	0.624				
	EC7	0.635				
	EC8	0.817				
	EC9	0.722				
SS	SS10	0.834	0.771	0.845	0.524	0.724
	SS5	0.721				
	SS6	0.69				
	SS8	0.643				
	SS9	0.717				

Table 1: Loadings, Reliability, Convergent Validity and Discriminant Validity Values

Note: CS=Caregiver Stress, EC=Physical Caregiving, SS=Social Support, CR=Composite Reliability, AVE=Average Variance Extracted

The results in Table 1 shows the satisfactory internal consistency reliability for all constructs with values 0.94, 0.92 and 0.84 for caregiver stress, emotional caregiving and social support respectively. For indicator reliability, all outer loadings were having values greater than 0.708 with few exceptions having lower values but showing AVE > 0.5. In addition, values of discriminant validity are also acceptable with higher squared root values of AVE than other constructs. In terms of assessment of outer loadings, 6 items were deleted showing low indicator reliability to increase the AVE which is only 20% of the indicators in the model.
Further, for assessment of structural model (inner model), the values of Variance Inflated Factor (EC= 1.71, SS=1.71) showed the absence of collinearity among constructs. Later, for the assessment of relevance and significance of the structural model, the PLS algorithm and bootstrapping was performed showing the values of path coefficient of all variables in Table 2.

Hypothesis	Relationship	Std Beta	Std Error	t-value	p-value	Decision	R^2
H1	EC -> CS	0.237	0.075	3.179	0.001	Supported	0.619

Table 2: Results of Hypotheses Testing (Direct Relationships)

In this study, 1 direct hypothesis was developed. Table 2 shows the results of the path coefficient where variables are found to have t-value > 1.645, thus significant at 0.01 level of significance. The predictors of emotional caregiving (β.23, p<.01) are positively related to caregiver stress which explains 61% of variance in caregiver stress. Therefore, H1 is supported. The R^2 value of 0.61 indicates a substantial model. Moreover, mediation took place with the bootstrapping procedure providing interval estimate of a population parameter.

Hypothesis	Relationship	Std Beta	Std Error	p-value	5.00 %	95.00 %	Decision
H2	EC > SS > CS	0.395	0.062	0.000	0.253	0.475	Supported

Table 3: Results of Hypotheses Testing (Indirect Relationships)

The results in Table 3 indicates that social support mediates the relationship between emotional caregiving and caregiver stress (β.39; p<.01). This provides the result of H2 of this study. The analysis revealed that emotional caregiving can leads to higher level of stress when examined directly whereas social supports acts as a mediator between emotional caregiving and stress of caregiver.

4. Discussion

Caregiving has found to be significantly associated with the stress of caregivers of children and adolescents with cancer (Litzelman, Catrine, Gangnon, & Witt, 2011; Soylu et al., 2015; Yousafzai, Bhutto, Ahmar, Siddiqui, & Selamat, 2011). The current study assesses the extent to which emotional caregiving and social support influence the caregivers' stress. The demographic characteristics of the caregivers mentions that most of the caregivers are females in middle age and an entire family to look after. Moreover, the caregivers do not have sufficient economical resources as they have minimal pay which indicates that the need to care for a cancer child costs not only emotional also financial.
The first hypothesis of this study that emotional caregiving would directly influence the caregivers' stress was confirmed. The finding that emotional caregiving to a child or adolescent with cancer was projecting to the caregivers' stress is in line with a study showing a significant relationship between the stress of caregivers in terms of providing physical or emotional caregiving (Long, & Marsland, 2011). These findings support Ellis (2012); and Beattie and Lebel (2011) studies who found that caregivers' stress was strongly influenced by emotional caregiving demands of the patient. The apparent impact of emotional caregiving on stress of caregivers has important directions for the service providers who identifies the caregivers with compromised health to provide additional support during the course of cancer treatment when emotional caregiving is highly demanded. Such support can possibly improve caregivers' mental health.
The second hypothesis which states that social support would mediate the impact of emotional caregiving on caregivers' stress was also supported. This finding provided evidence of a relationship between low caregivers' stress and social support. The extent of stress experienced by caregivers of cancer children is associated to the satisfaction and availability of the social support (Casale & Wild, 2012). Findings of the current study presents a notion that presence of social support within the family was considered as the most effective positive source of mental health. Generally, it is supported by a fact that people in Pakistan are living in closely knit families and friends who are usually ready to help the person when required. These findings are in line with preceding studies (Chambers, Girgis, Occhipinti, Hutchison, Turner, Morris, & Dunn, 2012; Marsland et al., 2013) who concluded that higher level of caregivers' stress was related to higher level of emotional caregiving especially in children with cancer. The findings indicate that the social support would lessen the effect of care giving on stress of caregiver. Particularly, social support was found to have a strong mediating effect on the caregivers' stress.
The results of the current study provided evidence of the influences of both emotional caregiving to patient and social resources of caregiver on experiences of caregivers and levels of stress during caregiving process. Many caregivers were susceptible to stress while others were already experiencing severe stress. Most of the caregivers acknowledged that support from family is satisfactory and adequate. Considering the stressful process of caring for a child with cancer, social resources are acknowledged as an imperative

component of comprehensive cancer care for caregivers. The findings highlight the need for health care systems to be well aware of the caregivers experiencing high strain, as these caregivers are the ones with compromised health.

In future, more research considering role of social resources could be conducted with respect to different types of diseases and caregivers in order to identify the means of improving mental health of caregivers. Clearly, further research is required to understand potential threat to caregivers' mental health due to the influence of caregiving process.

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